

Support Guide

for carers and families of people
with schizophrenia



This guide has been developed for carers and families of people with schizophrenia, to provide information about the services and support available in England both to the person you care for, and to you as a carer or family member.

When looking for answers about what support is available for you and the person you care for, there can often be so much information that it is difficult to find the answers you are looking for. This guide aims to provide enough detail to keep you informed, without overwhelming you.

The guide is broken down into the following sections:

1. Introduction to mental health services in England	02
2. Types of therapy and treatment	07
3. Care planning	09
4. Accessing care and support in a crisis	10
5. Your entitlements as a carer	11
6. Further information and support	12
7. My contacts	13

1.

Introduction to mental health services in England

Navigating the mental health care and support system can feel like a daunting task, especially if the person you care for is newly diagnosed and you have not had any interaction with these services before. People with mental health problems can require a number of different services, sometimes on an irregular basis, and it can often fall to a family member or carer to coordinate approaches to the various agencies. The diagram on the next page gives a snapshot of how someone with schizophrenia might journey through the mental health system and the various other services. It is important to note that everyone's experience is different, but this snapshot is intended to provide an idea of what a typical journey might look like.

First signs and symptoms and receiving a diagnosis

Schizophrenia can occur at any age but the first signs and symptoms usually start in early adulthood¹ and it is most often diagnosed between the ages of 15 and 35². There can sometimes be a delay between a person experiencing symptoms and receiving a formal diagnosis of the condition by a healthcare professional³.

Depending on a person's experience of schizophrenia, these early signs and symptoms might lead to contact with a range of healthcare and non-healthcare services including: general practitioner (GP) or family doctor services; hospital accident and emergency (A&E) services; inpatient hospital

services; social services; police or other criminal justice services; and voluntary sector services.

These services may then refer people on for further healthcare checks or investigations by a hospital doctor or what is called an 'early intervention service'. These checks may lead to a formal diagnosis of schizophrenia, at which point a total package of health and social care should be organised for the person you care for.

Ongoing management and treatment of schizophrenia

As outlined above, the person you care for can come into first contact with mental health services in a number of different ways. It is then the job of these services to provide the ongoing care and treatment needed to enable the person you care for to manage their condition effectively and receive support for their recovery.

Mental health NHS trusts provide health and social care services to people with mental health problems⁴. Mental health services can also be provided through your GP or through more specialist care, which may include counselling and other psychological therapies, community and family support (for example family intervention), or general health screening. More specialist care is usually provided through the mental health trust or local council, including services for people with severe mental health problems⁵.

1.

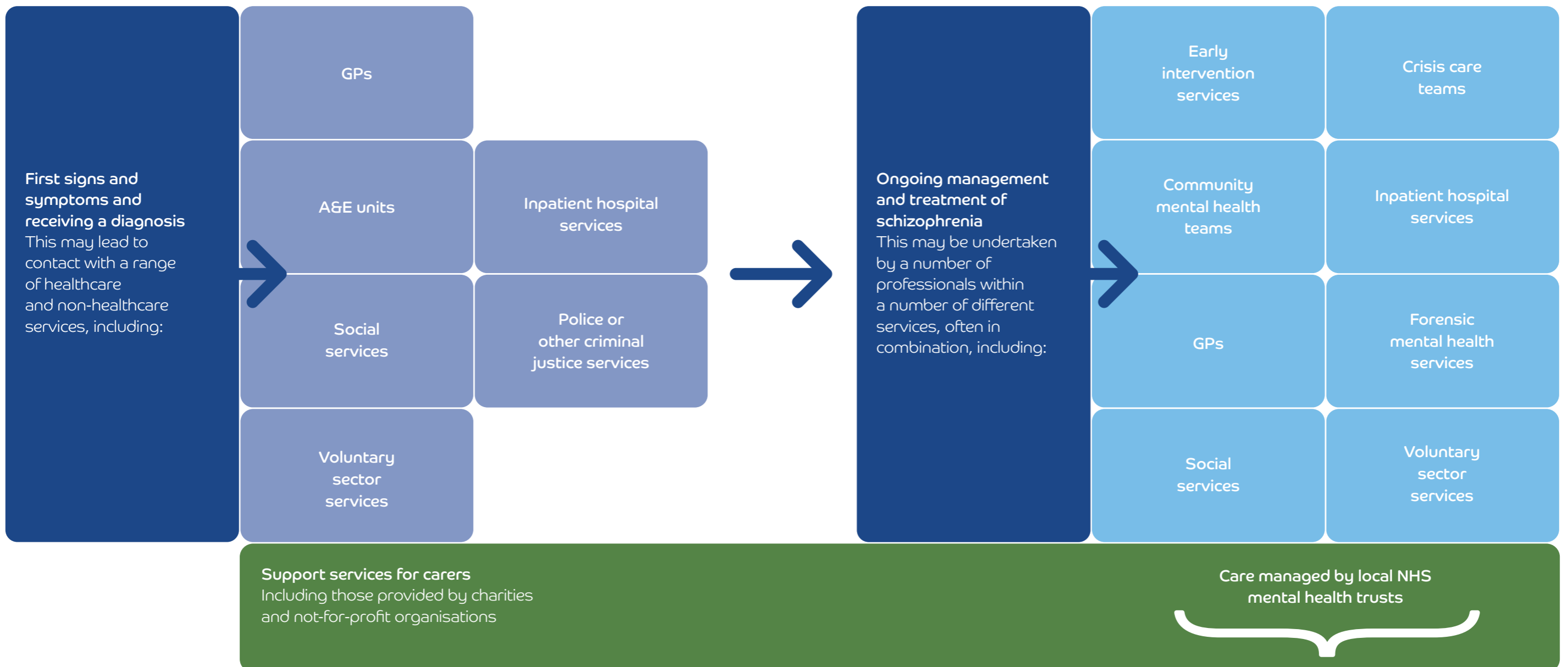
Introduction to mental health services in England

A sample journey through health and care services for a person with schizophrenia

Crisis care services

Referral to, or need of, crisis care services can happen at any time.

For details, see the 'Accessing care and support in a crisis' section of this guide



1.

Introduction to mental health services in England

Here is some more information about some of the services you and the person you care for might come into contact with:

- A **general practitioner (GP)** may be your first point of contact with the health service and often acts as a 'gatekeeper' for a range of other NHS services. They can prescribe some types of medication or refer a patient to other services, such as talking therapies or family intervention (there is more detail on these below)
- For people who may be experiencing their first symptoms of mental ill health, **early intervention services** offer support to help come to terms with what they are experiencing and to help the individual, and their carers and family members, to map out the services available to them. They usually support people within the first three years following the first experience of mental health problems
- People with a serious mental health problem like schizophrenia will often be referred to a **community mental health team (CMHT)** which organises care for a person when they are outside of a hospital setting. A CMHT may contain a number of different mental health specialists, including both clinical staff and social workers
- A person with schizophrenia will usually only be admitted to an **inpatient mental health service** if they are very seriously ill. These services are designed to provide a safe environment where people can access more intensive treatment and support. They provide an opportunity to engage with a range of clinical staff, including psychiatrists and therapists, as well as accommodation units for patients. The duration of an inpatient stay will vary according to the needs of the individual

The range of services across different geographic areas can vary significantly, reflecting decisions of the clinical commissioning group (CCG) responsible for organising healthcare in your local area. While there can be geographic variation, mental health services in your area should be designed in a way which ensures that each part of the system works well together.

- **Crisis teams (sometimes referred to as home treatment teams)** can give urgent help to people with a mental health problem during a crisis. Staff from a crisis team will aim to help an individual in their home, or other familiar setting, to keep them out of hospital or inpatient care. If the person you care for does not currently have a crisis team contact, this can be provided by your GP or another healthcare professional you have been in contact with
- **Forensic mental health services** mainly work with people with a mental health problem who have been involved with the police, courts or prison service. These services may be provided in the community or in a secure hospital and are usually for people who have been detained or 'sectioned' under the Mental Health Act

It is also important to note that a number of **voluntary organisations** offer support and information services for people with mental health problems as well as their carers and families. More information about some of these organisations, and contact details, can be found in the 'Further information and support' section of this guide.

2. Types of therapy and treatment

NICE recommends that people with schizophrenia should also be offered **medication** to manage their condition. This is known as ‘**antipsychotic medication**’ and is usually prescribed by healthcare professionals as part of a package of care, which may also include CBT or a FIP. People affected by schizophrenia should be provided with timely, accurate, and high quality information about the condition, the different treatment options available and potential side-effects of medications. Choice of medication should be made by the patient and healthcare professional together, taking into account the views of family and carers, if the person with schizophrenia agrees. This should be a meaningful ongoing discussion amongst all involved in the care planning process based on trust, familiarity and continuity of care.

When in contact with these different services, the person you care for might be offered a range of therapy and treatment options.

Below are some details explaining what to expect from the various types of therapy and treatment:

- **Talking therapies (or talking treatments)** might be offered in a number of forms – there is no single ‘talking therapy’ – and different types may be used to help someone with schizophrenia to manage their condition. Talking therapies include counselling, cognitive behavioural therapy (CBT), psychotherapy and family intervention. Further details on some of these types of therapy, as well as others, are provided below
- One of the most common types of talking therapy is **cognitive behavioural therapy (CBT)**. The National Institute for Health and Care Excellence (NICE), which is the body responsible for setting out what care you are entitled to, states that CBT should be offered to all people with schizophrenia⁶. CBT sessions, which are directed by a trained therapist, are clearly structured and focused on current problems and practical solutions, often setting short-term goals with the person receiving treatment
- **Family Intervention Programmes (FIPs)** are commonly used to help improve the care of people with mental health problems. FIPs are designed to be tailored to the people involved and can be offered to any carer or close friends who occupy a ‘caring role’ for someone with a mental health problem. A FIP may include strategies such as teaching friends and relatives about the symptoms and signs of a particular mental health problem and improving communication channels to better cope with them
- **Ecotherapy** is designed to involve a range of outdoor activities which might include gardening, hiking or cycling through a scenic area (sometimes in a group), for example, as part of a designated conservation project
- **Arts therapies** use drama, dance, music and art to help someone manage their symptoms. Both eco and arts therapies have been shown to be effective in the management of a mental health condition, and are often used in combination with medication and CBT^{7,8}

3. Care planning

A care plan is an agreement between a patient and their healthcare professional, or social services, to help them manage their health on a day-to-day basis.

A care plan should set out the support that will be provided to the person you care for, and who will provide it to them. It should be a 'live document' shared between you, the person you care for and a care coordinator. Each of you will be able to contribute to the care plan and to share your views of what it should contain.

It can be easy to feel that you might not be listened to in the care planning process. This can particularly be an issue where the person you care for has not given consent for the professionals involved in their care to share confidential information with you. You can discuss this with the person you care for, and they can sign a consent form for the professionals involved in their care to share as much or as little about their care with you as they like⁹.

NICE guidance recommends that a care plan should be written as soon as possible after a person is assessed and diagnosed with schizophrenia. The NHS England Mandate (which sets out the Government's annual ambitions for the NHS) made it an objective to ensure that by 2015:

"Everyone with a long-term condition, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions".

The person you care for should have a care coordinator, and this person will work with them to develop a care plan¹⁰. A care coordinator could be a social worker, community psychiatric nurse or an occupational therapist. The mental health team who support the person you care for can also help you with the care planning process, and may be able to give advice as to what you should try to include. The care plan should be written as a collaboration between the person it is being written for, their care coordinator and their carer – with a copy of the plan then being sent to the healthcare professional or service who/which made the first diagnosis.

SANE, Lundbeck and Otsuka have published an accompanying resource to this guide, Preparing for schizophrenia care planning, which provides more information on how you can play an active role in the care planning process, from preparing for discussions to putting the care plan into action.

4. Accessing care and support in a crisis

Even if the person you care for has the right care and treatment in place to support them to manage their condition, they may still experience times of crisis. Planning is vital to ensure that, if crisis care is required, everyone involved feels well prepared to respond and is aware of the support available to them. As the diagram below shows, responding to a crisis for someone with schizophrenia can involve a number of parts of the mental health system, often working in combination. As part of the care planning process, you should work with the care coordinator to include a plan of action for dealing with a crisis, including noting down a designated crisis contact. This may be a

member of your community mental health team, a GP, or another healthcare professional you have engaged with.

The person you care for can also provide an 'advance statement', which would explain what they would like to happen, and what information they would consent to being shared, in the event of a mental health crisis or relapse through which they may lose the ability to make decisions for themselves.

Contact numbers are included in the 'further information and support' section of this guide, which may be useful if you are dealing with a mental health crisis.

Mental health services which may be involved in crisis care:



5. Your entitlements as a carer

If you have not been offered the carer's assessment that you are entitled to, you should contact the local authority adult social services department providing support to the person whom you care for to request an assessment.

As well as being aware of the various organisations that can provide care and support for the person you care for, it's also important that you know what you are entitled to as a carer. The 2014 Care Act introduced new legal rights for carers including, from April 2015, the entitlement to a carer's assessment with your local authority, which should be offered to anyone who identifies themselves as a carer.

A carer's assessment should look into how caring affects your life, including your physical, mental and emotional needs, and whether you are able or willing to carry on caring. After your assessment, you can agree a support plan with your local authority which will set out how your needs will be met in the future.

A carer's assessment might reveal issues that should also be covered in the care plan of the person you care for. If your carer's assessment shows that the time

that you spend caring for the person with schizophrenia is having an impact on your physical or mental health, you might try to reduce this impact through your carer's support plan.

If the person you care for is detained under the Mental Health Act you also have a right to request an assessment to determine whether they should be detained; or that they are discharged. Even in this situation, rules on data sharing and confidentiality remain unchanged meaning that you will not be able to gain access to information which the person you care for has not consented to be made available to you. The only exceptions to this would be in the event that an advance statement has been agreed (as detailed above) or where the approved mental health professional needs to consult with you relating to an admission under Section 3 of the Mental Health Act¹¹.

6. Further information and support

You can find more information about care planning and the support available to you and the person you care for at:

- SANE: www.sane.org.uk
- The Royal College of Psychiatrists: <http://www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/checklistforcarers.aspx>
- Your local authority website, as they may provide services for carers

In the event of a crisis, you can contact **SANEline, which provides emotional support and information to anyone affected by mental illness, including families, friends and carers, between 6.00 and 11.00pm 365 days a year on**

0300 304 700

